



# “It’s improved the whole lifestyle”: Exploring the family perspective of participation in a Gavel Club for people with aphasia

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**Purpose:** Aphasia impacts not just the individual with aphasia, but also their family members and friends. Known as third-party disability, it is largely hidden but can be as pervasive as aphasia itself. Gavel Clubs are a Toastmasters International-affiliated group where members participate in public-speaking tasks. Participation has been associated with improvements in quality-of-life and communication confidence but the extent to which it can impact family members of people with aphasia is not yet known. This study explored family member perspectives of participation in a Gavel Club for people with aphasia, to reveal any benefits or challenges perceived by family members and/or close friends.

**Methods:** Semi-structured interviews were undertaken with 13 family members or close friends of people with aphasia who regularly participated in a weekly Gavel Club. The interviews were analysed using thematic analysis.

**Results:** Three themes were identified: (1) Something to do, (2) Sense of community and (3) I can see great improvements, along with two subthemes (i) This is not just us and (ii) Support of knowing other people go through it. The themes reflected a largely positive experience of Gavel Club participation as perceived by family members. The theme names were derived from quotes from the participants.

**Conclusions:** Regular participation in a Gavel Club for people with aphasia has a positive impact beyond just the person with aphasia, extending to their family members and close friends. This impact can be direct, if the family members themselves participate, or indirect, through the perceived benefits for the person with aphasia.

**Keywords:** Aphasia, Family members, Gavel club, Community group, Third-party disability, Thematic analysis



**Received:** June 25, 2021  
**Revision:** January 14, 2022  
**Accepted:** August 26, 2022

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## INTRODUCTION

Third-party disability describes how an individual’s health condition impacts on their family members [1]. The impact, which can be sufficient to affect the person’s ability to function in daily life, may include worrying about their family member’s health, or having to take on greater responsibility for tasks to compensate for changes in their family member’s functioning. Scarinci, Worrall and Howe [2] described the impact that an individual’s hearing impairment can have on their spouse. This included difficulty communicating one-on-one with their partner, having to support their partner in conversa-

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tion with others, and adverse effects on their marital and sexual relationships. Although the authors found no physical impact on spouses, it has been suggested that the stress and energy associated with caring for a family member with a disability may affect one's physical wellbeing [3].

Aphasia is caused by damage to the brain and affects a person's ability to comprehend and express language across all modes of communication [4]. Common symptoms of aphasia include a reduction in understanding verbal and/or written information and a word-finding difficulty [4,5]. Due to the pervasive nature of aphasia (with both receptive and expressive language difficulties), it can substantially impact on romantic relationships [6], friendships [7,8], and employment [9].

### Effects of aphasia on family members

Family members of people with aphasia (PWA) have been referred to as the 'hidden victims' of aphasia, due to the negative impact it can have on their lives, and the lack of support or interventions available to them [3]. When compared to caregivers of stroke survivors with no aphasia, caregivers of those with aphasia had more significant depressive symptoms and worse stroke-related caregiver outcomes, including lower energy levels and financial wellbeing [10].

Le Dorze and Signori [11] interviewed the spouses of PWA to understand their needs. The participants expressed a need for support; a need for more time for themselves to engage in their own activities and have a break from their caretaking role; a desire for the PWA to participate in activities that did not require family member involvement; and wanting to see their spouse's communication abilities improve, in the hope that this would improve their relationship. Factors could act as both facilitators and barriers to meeting the needs of family members. Either they were unable to find services that provided support, or the available services were difficult to access. Brown, Worrall, Davidson and Howe [12] interviewed 24 family members of PWA about their perspective of living successfully with aphasia. They reported that aphasia can affect the whole family and therefore family members' needs and priorities ought to be considered.

In their qualitative study Grawburg, Howe, Worrall and Scarinci [13] described the experiences of family members of PWA using the World Health Organisation's International Classification of Functioning, Disability and Health (known as the ICF framework). Twenty participants, including grandchildren, children, spouses, siblings and parents of PWA re-

ported changes in both the 'Body structures and functions' and 'Activities and participation' components of the framework as a result of their loved one's aphasia. Domestic life was particularly affected, with many participants reporting they were now primarily responsible for household tasks due to the reduced abilities of the PWA. They also experienced changes in their relationship with their family member due to aphasia. Family members reported differences in *how* they communicated as well as differences in what they communicated *about*. Time for family members to spend on their own activities was diminished because of the time spent focusing on the PWA. Although many of the changes reported by members of the family were negative, most participants reported positive changes as well, including being proud of their family member for facing the difficulties that aphasia brings, valuing their relationship with their family member more and an increase in tolerance and acceptance of others. Despite this, the study highlighted the challenges that family members face due to their loved one's aphasia and indicated that interventions should be in place to target their needs. Collectively, these studies emphasise the importance of understanding the impact of aphasia not just on the PWA but on the family as well.

### Community groups

Community groups are a common way that PWA can get support alongside or following the completion of traditional speech-language therapy. Community groups can provide new friendships, and membership in a weekly aphasia group has been associated with lower perceived social isolation, stronger social connections [14], greater participation and a space where communication difficulties are commonly understood and shared [15,16]. A study of long-time group members and those who had left groups revealed a sense of belonging, contribution and companionship for those who had maintained membership and feelings of rejection and exclusion by those who had left [17].

Community groups for PWA have also been found to have an impact on the family members of participants too. Rotherham, Howe & Tillard [18] conducted interviews with ten PWA who had participated in community groups and six of their family members. Ten benefits of community groups were identified by the family member participants. These included improved communication between the family member and the individual with aphasia, support and social connection for the family member, as well as giving family members time to

themselves while their loved one attended the community group.

### Gavel Clubs

Gavel Clubs (GCs) are a community group that can be explicitly designed for PWA. They are an adapted form of Toastmasters International for people who choose not to join a regular group [19]. They use public-speaking to build skills in communication, confidence, and leadership [19]. GC meetings typically include impromptu speeches (1-2 minutes long), and prepared speeches (approximately 6-8 minutes long). Group members evaluate both speech types for what they liked and, what could be improved. Generally, speeches are evaluated on their structure, effectiveness, vocal variety and use of body language. While most members participate in impromptu speeches (known as 'Table Topics') every meeting, the prepared speeches are voluntary, with members completing 2-4 of these each year [20]. Family members often support the GC member in the planning and practising of their speech and by producing communication aids such as PowerPoint slides or props. GCs also provide members with an opportunity to take on leadership roles, such as club president (elected annually by members), or positions related to the structure of the weekly meetings, such as Toastmaster, who introduces the speakers, and evaluators. Family members of PWA are welcome to attend GC meetings either as a support person or to take on other roles such as treasurer or time-keeper.

The current study aimed to examine family members' perspectives of weekly GC participation. Although the primary purpose of a GC is to provide support for PWA, we sought to understand any impact on the family of GC members. Previous research has shown that GC membership is associated with improvements in communication confidence and quality of communication life [21] as well as improvements in conveying linguistic content and grammaticality [22]. This qualitative study will add to existing literature in the area of aphasia-specific community groups.

## METHODS

A two-step recruitment process was utilised to ensure that PWA were happy for their family member to be interviewed. All GC members were given information about the study (verbally and in writing), and were invited to pass it on to their family member if they were happy for their family member to

participate. The family members themselves contacted the researchers if they wished to participate. An important aspect of this study is that the PWA chose who they gave the information to. The authors had intended for this to be family members, but two PWA decided instead to ask their very close friends. Ethics approval (including guidance on the plans for sensitive recruitment) was attained through the University of Auckland Human Participants Ethics Committee (protocol number: 022668).

In total, 13 participants were recruited, 10 females and 3 males. The relationships between the participants ( $n=13$ ) and the PWA ( $n=11$ ) included marriage/life partner ( $n=9$ ), close friend ( $n=3$ ) and daughter ( $n=1$ ). For two of the PWA, two participants were recruited; the wife and daughter of one PWA and two close friends of another. The term "family member" is used for consistency throughout even though three participants were very close friends rather than biological family members. Readers are reminded that the PWA were *not* the participants, but in the interests of clarity their aphasia was diagnosed with the Western Aphasia Battery [23]; 8 with fluent aphasia and 3 with nonfluent aphasia, which they had been living with between one and twenty-five years ( $M=8.77$ ,  $SD=7.935$ ). They had been attending the GC for an average of 3.9 years ( $SD=2.64$ ). Participant details (i.e., family members) and those of the corresponding PWA are presented in Table 1.

### Interviews

Semi-structured interviews [24] were carried out individually, either face-to-face or electronically over video (in a location of their choosing). The average duration of the interviews was 33 minutes (range; 23 to 73 minutes). The interview that took place with the wife and daughter of a GC member was considerably longer than average. The interviews with close friends were generally shorter than interviews with family members and were all less than 25 minutes long. The interview questions (provided in Table 2) were developed specifically for this study and were focused on understanding how the PWA's participation in the GC had impacted participants. Interviews were audio-recorded, then transcribed verbatim by the first author. Notes that came up during the transcription process were documented for possible use in the analysis.

### Analysis

The interviews were analysed using thematic analysis [25]. The process of transcribing each interview aided familiarisation with the data. An inductive coding approach was used

**Table 1.** Participant (family member) details and the corresponding PWA

| Participant number | Family member |                     |                       | Corresponding GC member with aphasia |                                       |   |
|--------------------|---------------|---------------------|-----------------------|--------------------------------------|---------------------------------------|---|
|                    | Gender        | Relationship to PWA | Regular GC attendance | Gender                               | Time post-onset (months, approximate) | Time attending GC (months, approximate) |
| 1                  | F             | Partner             | No                    | M                                    | 72                                    | 60                                      |
| 2                  | F             | Wife                | No                    | M                                    | 36                                    | 24                                      |
| 3                  | F             | Daughter            | No                    | M                                    | 24                                    | 16                                      |
| 4                  | F             | Wife                | No                    |                                      |                                       |   |
| 5                  | F             | Wife                | Yes                   | M                                    | 12                                    | 9                                       |
| 6                  | F             | Wife                | No                    | M                                    | 150                                   | 24                                      |
| 7                  | M             | Husband             | Yes                   | F                                    | 144                                   | 96                                      |
| 8                  | M             | Husband             | Yes                   | F                                    | 108                                   | 96                                      |
| 9                  | F             | Wife                | Yes                   | M                                    | 24                                    | 18                                      |
| 10                 | F             | Wife                | Yes                   | M                                    | 300                                   | 96                                      |
| 11                 | F             | Close friend        | No                    | F                                    | 36                                    | 24                                      |
| 12                 | F             | Close friend        | No                    |                                      |                                       |   |
| 13                 | M             | Close friend        | No                    | M                                    | 240                                   | 96                                      |

**Table 2.** Semi-structured interview questions

|   |  |
|---|--|
| 1 | How has _____'s [name of family member/friend] participation in the Gavel Club (GC) for people with aphasia affected you?<br>Have there been any changes in your relationship as a result of their membership of the GC? |
| 2 | What do you perceive to be the benefits of attending the GC for people with aphasia?   |
| 3 | What, if anything, have you found challenging about _____'s [name of family member/friend] participation in the GC?  |
| 4 | What happens over the summer break when there are no GC meetings for several weeks? Do you notice any changes in you, your partner or your relationship?   |
| 5 | If you were approached by someone whose family member had aphasia, what would you tell them about the GC?  |
| 6 | Is there anything else about _____'s [name of family member/friend] participation in the GC that you would like to discuss?  |

and codes were created based on the content of the data. On the completion of initial coding, 63 codes had been generated. These were visualised on a concept map to examine the relationships between the codes and to establish initial themes. Through this process, several codes were collated based on their similarity and two were removed because there was insufficient data to support them. The initial themes were reviewed through discussion between the researchers, and any discrepancies clarified. Three themes and two subthemes

were finalised as describing the family perspective of GC participation. The fifth phase of thematic analysis is defining and naming the themes. In order to do this, we defined the themes and subthemes and then searched for relevant participant quotes to use as theme names. NVivo 12 software was used for transcribing and analysing the data to ensure consistency [26] and thematic analysis processes were followed very closely to enhance rigour [25].

## RESULTS

Three central themes were titled using participant quotes: (1) "Something to do", (2) "Sense of community" and (3) "I can see great improvements". Within the "Sense of community" theme, there were two subthemes: (i) "This is not just us", and (ii) "Support of knowing other people go through it". Throughout the interviews, there was a sense that the participants were on a journey towards acceptance of the impact aphasia had on their lives. Although this journey did not exist solely in the context of the GC (and is therefore not a theme per se), it appeared that engagement with the GC was one of the ways participants and the PWA progressed towards acceptance.

### Something to do

Participants described how the GC had given the PWA an activity to fill their time, which had become emptier as a result of aphasia. Participants also thought that having an activity

helped PWA develop a sense of purpose in life. As participant 13 said:

Someone like him goes from you know being a busy person to, ... obviously a person with disabilities, and things are a lot more limited, um, ... something to, ... that is a date in the calendar every you know, on a regular basis, that ..., gets him across the city and gets him moving and gets him doing things, ... I mean um all these things all give a ... purpose ... to an existence.

Participants also felt that certain aspects of the GC benefited PWA. For example, everyone is required to contribute, even if just introducing themselves. Some participants felt the need to assist the PWA by helping them to prepare for meetings.

In terms of preparing these talks, his written English is worse than his speech, so if he's doing slides or doing questions for Table Topics or something. He, he needs help with what he writes ... I'll have to try work out what he's saying, and then, and then he gets very annoyed with me because I should know what he's meaning (Participant 1).

The participants who regularly attended the GC, and had roles within the GC, said it gave them something to fill their time: "It just gives you another activity to be involved in so it's quite good really, cause I've got the time and I've got the ability to do it so why not do it?" (Participant 8).

This theme was also evident in responses from participants who did not regularly attend. However, the benefit was that it gave them respite or time to themselves while the PWA attended meetings. These participants said they spent a lot of time with the PWA, so having a few hours apart each week, gave them something to talk about when they were together again: "He's always got like a debrief, like his stories for the next few days are like "Oh, at Gavel Club we did this, we did this" for like three whole days" (Participant 3).

Participants described feeling less concerned about the PWA as a result of them having the GC and other activities as part of their routine:

I feel a little more relaxed, I guess, or less um, responsible to, um, engage her or keep her happy, and I think she's got a routine now that works for her and the Gavel Club would be a big part of that (Participant 11).

Some of the participants described the PWA as very busy, and the GC was only one part of their routine. For those participants, having a summer break from the GC did not greatly impact their lives. However, other participants found that the PWA was impacted to a greater degree by the breaks:

I said, "are you sick?" cause he was still in bed, and he's like "Ah, well, what's the point in getting up?" Now, that could be on any day, but I think, it, it definitely has, it contributes to isolation and a lack of purpose, these great big long gaps that you have (Participant 1).

### Sense of community

Family members thought that the GC provided a sense of community for the PWA. The impact of this community was also felt by the participants, although the extent to which it was felt depended on how involved they were with the GC. Within this theme two subthemes exists: (1) "This is not just us" and (2) "Support of knowing other people go through it". In general, participants felt the GC was an environment where PWA could socialise and spend time with others:

People you don't think would talk to each other, you know, um all of a sudden are nattering away you know, and the, and the speech is terrible, you know. Just unbelievable, you wonder how they communicate, but both sides understand that you know, what's going on. And um, you know they like to stick at it until they find out what they want to tell ya (Participant 7).

The impact of the GC on the family member resulted in a reduced sense of responsibility regarding the PWA's social wellbeing and participants were happy they had found a sense of community. "Mostly pleased to see that she is engaged in something that makes her feel valued" (Participant 11). The participants who regularly attended the GC themselves felt they were personally a part of the GC community as well:

So, for me it was uh, really nice to have that social contact, to um to enjoy being with a group, to be welcomed by the group as well and feel that, that they were accepting that you were part of it (Participant 10).

### (i) *This is not just us*

Family members noted that the GC was beneficial socially because it catered specifically for PWA: "For somebody in his situation, it's very isolating. So actually, providing a-anything, where people, particularly people with the same issues, come together is extremely valuable" (Participant 1). It was perceived that family members of PWA were not alone in the difficulties that they faced, and this helped them accept their situation. Participant 2 said:

Oh, I think this they realise, he's not the one who's affected by that, there are so many other people. At the very



beginning [name of husband] and even my children couldn't understand what happened to us and why, why, why? But when you go and be among with those people, oh this is not just us.

One participant thought that her husband felt more comfortable talking at GC meetings because he knew that the other members had aphasia too:

He knows that this person is the same as me, all those crook [unwell] peoples coming here, so he's not shy with anyone with over here. But at home, someone comes, he never answers the phone, he never talks to anyone (Participant 9).

The fact that all the GC members have aphasia also allowed both family members and PWA to compare themselves to the other members of the group. Most of the participants felt this comparison gave the PWA a sense of confidence in their own abilities. These comparisons had flow-on effects for some of the family members, who felt more grateful for their circumstances:

Me, I, I think how lucky I am, whereas, uh for the for [name of wife] it's, "I'm not as bad as her" and then, she will be saying "well, I'm not as bad as that person", and you, you know it sort of goes down the chain a bit (Participant 7).

Family members also described a sense of hope for future recovery that they felt PWA got by spending time with each other.

When he goes to GC, um there are so many other people and he knows, he has that mmm idea in his mind he can recover as well, because ... he knows the story of the people who recovering gradually although it takes long years, still there's a hope, and that's a very good thing (Participant 2).

### ***(ii) Support of knowing other people go through it***

Family members described the GC as a place where they and the PWA could be supportive and supported. Some family members regularly attend the GC as a support person, these participants enjoyed seeing the GC members help each other at meetings. Participants who attended the GC also felt they were able to access support for themselves. As participant 5 said:

We just had a meltdown because um, I guess I was just getting sick of being expected to do everything, and I said something to one of the wives there about um having a meltdown, and she told me about her, their meltdown, ac-

tually years ago, but you know at the beginning of their aphasia journey, and it just made me thought well yeah, you know, of course, I'm going to get frustrated with what's going on.

Family members who provided support for others also experienced a sense of fulfilment:

I guess it's passing on your own experience, and um, you know, and feeling for them because I've, we've been through that space as well and, and you feel for them, so you want to say it does get better or, you know, provide them an encouragement or know that they're not alone. Um, because we've been through it, and um, you know, for the people who are new to it, it's a pretty scary place (Participant 10).

### **I can see great improvements**

Participants described changes and improvements they had seen since the PWA joined the GC. Many of the improvements they discussed were quite general, in that participants felt they were seeing a progression in the abilities of the PWA. Although it is unclear whether these improvements were a direct result of GC participation, participants felt it played a role. As participant 4 said: "if there hadn't been a GC, I think he might've not made so much progress".

Many of the participants reported that the PWA's speech had improved in the time since they joined the GC:

What I have seen, as I say, is just an enormous, particularly over the last year, a tremendous improvement in her, uh, in the clarity of her speech and her ability to get, because I know that she knows it up here, very well, there's, there's no, no doubting about that, it's just being able to get, um, the fullness of what she wants to say across (Participant 12).

Some of the participants expressed a sense of pride and were inspired by the achievements of the PWA. There were also practical implications for families in terms of improvements in communication: "Um, well just because he's getting more fluent and more enthusiastic so, it, it makes, makes certain things easier, you don't feel isolated so, so I think that's the best thing" (Participant 4).

Confidence was another area of improvement that family members attributed to the GC. This change was often conceptualised in terms of their participation in GC meetings:

I've been going there long enough now, people do gain in confidence in their ability or their speaking. Where in the past they really wouldn't say much at all, but they

slowly over a period of time, their confidence and they do speak and get involved more and more (Participant 8).

The improvement in the PWA's confidence had a further impact on the participants: "By him feeling more confident about it, I guess that that rubs off on me too" (Participant 6). Similarly, family members noticed improvements in independence in social settings and the ability to carry out activities in daily life such as arranging transport. The independence of the PWA often had a direct impact on the participant: "makes me a little bit, you know, a lot more relaxed and um, you know, I'm comfortable we can get on with just living our lives normally rather than him being as dependent" (Participant 10).

Family members also reported seeing an improvement in the PWA's mood, which they derived a sense of pleasure from: "he's very happy, he, he brought, brings that happiness to home" (Participant 2). For some participants this happiness was especially important as they felt it improved the PWA's symptoms: "when he's buoyant and you know, in a good place, then it, everything flows and not just his speech flows, but his understanding flows as well" (Participant 10).

Two of the participants who regularly attend the GC also noted improvements in their own confidence and public speaking abilities:

I've never been able to stand up in a group of people, and of course, I have to, to introduce myself so and I think well if they can do it, I can do it, so in a way, it's benefitting me (Participant 5).

### Journey towards acceptance

While a not a theme, a number of the participants spoke in the interviews about the impact that aphasia had on their own lives and that of the PWA. This occurred in a variety of ways. The participants who had been living with aphasia for a short period of time spoke more about the initial process of rehabilitation and the progress they were hoping to see: "I just think it's gonna keep improving, like, I don't, I don't know if it will plateau but, it doesn't, it's definitely not plateauing yet" (Participant 3). However, the participants who had lived with aphasia for a longer period of time talked more about a sense of moving on and coping with the everyday challenges they continued to face. Within this, there was also a sense of gratefulness for what they still had: "You don't grieve for what might've been, but ... the fact that we still have [name of husband] with us, is ... the best part about it. Like we can cope with the speech, cause I've still got him" (Participant 10).

## DISCUSSION

This study was the first to seek an understanding of how participation in a GC for PWA can impact the family members of GC members. The study revealed three themes that describe the family perspective of GCs for PWA: (1) Something to do, (2) Sense of community and (3) I can see great improvements.

"Something to do" revealed how participants viewed the GC as one way in which the PWA was able to fill their time. Family members who did not regularly attend the GC described a reduced sense of responsibility and enjoyed having time to themselves while their loved one attended GC meetings, much like earlier research [13]. Those that attended GC meetings experienced this more directly, because it gave them something to do as well. Many PWA are unemployed and may be limited in finding activities that suit their communication needs, which can result in a reduced sense of purpose [9]. For our participants the GC provided a sense of purpose for the PWA, allowing the participants to feel less responsible in this area. Spouses of PWA desire time to themselves [11,12], it appears that family members with a need for respite were able to achieve this by having the PWA attend GC without them.

Family members felt the GC created a sense of community. Within this theme were two subthemes of (i) This is not just us, and (ii) Support of knowing other people go through it. The first revealed how being around other PWA reduced family members' feelings of loneliness and provided them with a sense of hope for the PWA's recovery. This echoes the need for hope reported by PWA and their families in terms of rehabilitation goals [27]. Hope has been established as an essential aspect of living well with aphasia [28], and is thought to be related to social support [29]. The second subtheme, similar to previous research, revealed how PWA were able to access support through the other GC members and their families [15]. This subtheme suggests that the GC can be a useful way for family members of PWA to achieve their own goals of support [11]. The communication benefits of GC attendance have been documented previously [21,22], as have the psychosocial benefits of aphasia group participation [18]. The sense of community depicted in the current study further reinforces this relationship between psychosocial wellbeing and communication support.

The final theme of "I can see great improvements" revealed how participants felt that the GC had contributed to the PWA's progress in communication. The impact of this improvement on the family included decreasing feelings of isolation, and

feeling that the PWA was less dependent on them in day-to-day life. This theme supports previous findings that GCs can improve the communication confidence of PWA [21]. It also suggests that improvement in confidence extends beyond GC performance and impacts their communication in daily life. Furthermore, it suggests that GCs may assist family in improving their communication and relationship with the PWA [11,12]. An improvement in mood was described by some participants, and they felt this too had a positive impact on the PWA's communication. Some of the participants who attended the GC saw improvements in their own public speaking abilities as a result of attending. It is therefore likely that being more involved in the GC results in family members experiencing direct impacts of the club.

Some participants expressed acceptance of the impact that aphasia had on their lives. This was especially apparent in participants for whom life with aphasia had become routine, and they had learnt to accept and adapt to the difficulties that aphasia can bring. This is supported by previous studies where family members described living successfully with aphasia as a journey [12]. Although the journey is not unique to the GC, family members' comments indicated that engagement with the GC contributes positively to this journey for both the PWA and the family member.

Throughout the three main themes of this study, we found that family members were both directly and indirectly affected by the GC. Those that attended GC meetings regularly had their own experience of the club and strongly felt that they were part of the community. They also spoke of being inspired by the progress made by PWA at GC meetings. Family members who did not regularly attend meetings were indirectly affected by the impact that the GC had on the PWA.

While this study focused specifically on the impact of GCs, other community groups for PWA may have a similar impact on family members. Many groups provide PWA with a sense of purpose and an avenue to meet new people [14,16]. Groups which specifically cater for PWA allow members to spend time with others facing similar difficulties which can enable PWA to see first-hand what living successfully with aphasia is really like [15]. These effects likely impact the families of PWA in similar ways to that seen in the current study, as families might feel less pressure to provide a sense of purpose and social connection for the PWA [17]. Unique aspects of the GC may provide further avenues by which family members can benefit. GCs emphasise participation by PWA, and thus improvements in communication may be more evident. GCs

also allow family members to decide how involved they would like to be, which allows them to prioritise their own needs, whether they need respite or support.

While these groups are not a replacement for rehabilitation which directly targets family needs, such as communication partner training [30,31], it does suggest that community groups can directly benefit families. The impact of GCs on family members may be understood in terms of third-party aphasia. These results primarily relate to the activities and participation component of the ICF framework [1]. In particular, association by PWA with the GC may alter family members' third-party disability in the domains of communication, interpersonal relationships and community.

### Limitations

While the current study has contributed to an understanding of the impact of GCs on family members of PWA, there are some limitations. Our study has only included participants from a single GC, it is possible that other GCs do not impact PWA and their families in the same way. However, given that many community groups for PWA have been found to impact social connection and a sense of purpose [14,15], it is likely that other GCs would exhibit similar effects to those described here. Our study was also only able to reach the family of PWA who were still attending the GC regularly. The family members of PWA who have left the GC may have different opinions, as was the case in a recent study [17]. However, very few PWA have left the GC since its inception, making this a difficult group for us to sample. Nevertheless, future research would benefit from involving more GCs and both past and present members to establish whether the impact of this GC is unique among aphasia groups.

Another potential limitation is that some GC members did not pass the study information onto their family members, or the family members chose not to participate. It is possible that those who did participate perceived positive benefits which they wanted to express. Non-participants may have had different or less positive views. Recruiting a wide range of family members (including close friends), some of whom were not directly involved in the GC, is likely to have reduced the impact of self-selection bias but this cannot be ruled out.

### CONCLUSION

The results of the current study suggest that family members view GC membership as a positive aspect of the lives of PWA.



Furthermore, GC can impact the lives of family members directly by participating themselves, and indirectly through the GC's impact on their loved one.

Clinicians should consider the direct and indirect benefits of GC membership when addressing third party aphasia in family members. Membership appears to be particularly beneficial for family members with needs in the domains of communication, community and interpersonal relationships.

Future studies should continue to include family perspectives when considering the impact of aphasia. Studies may also benefit from incorporating the use of tools such as the FAMLI scale [32] to measure the benefits of groups like GC for families. This could also be used to compare different types of community groups to determine which are likely to be more beneficial for different PWA. Longitudinal methods and use of controls would benefit future research by allowing studies to determine whether results can be solely attributed to group membership.

This study gave a voice to family members of PWA. Typically, they are significantly impacted by aphasia but do not usually have the opportunity to discuss this. We therefore give the last word to participant 10 who concludes with her perspective:

From my point of view the Gavel Club has been hugely successful ... and, it has provided much, much more than just improving people's speech. It's, it's improving in ... based on our experience, it's improved the whole lifestyle, the whole um, social aspect, the, sense of belonging, yeah, I mean it's just, incredible what it's achieved I think.

## ACKNOWLEDGMENTS

The authors would like to acknowledge Julie Plourde for her support of this study and the family members who willingly participated.

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